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Grief after second-trimester termination for fetal anomaly: a qualitative study

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Abstract

Objectives—We aimed to qualitatively evaluate factors that contribute to and alleviate grief associated with termination of a pregnancy for a fetal anomaly and how that grief changes over time.

Study design—We conducted a longitudinal qualitative study of decision satisfaction, grief and coping among women undergoing termination (dilation and evacuation or induction termination) for fetal anomalies and other complications. We conducted three postprocedure interviews at 1–3 weeks, 3 months and 1 year. We used a generative thematic approach to analyze themes related to grief using NVivo software program.

Results—Of the 19 women in the overall study, 13 women's interviews were eligible for analysis of the grief experience. Eleven women completed all three interviews, and two completed only the first interview. Themes that contributed to grief include self-blame for the diagnosis, guilt around the termination decision, social isolation related to discomfort with abortion and grief triggered by reminders of pregnancy. Social support and time are mechanisms that serve to alleviate grief.

Conclusions—Pregnancy termination in this context is experienced as a significant loss similar to other types of pregnancy loss and is also associated with real and perceived stigma. Women choosing termination for fetal anomalies may benefit from tailored counseling that includes dispelling misconceptions about cause of the anomaly. In addition, efforts to decrease abortion stigma and increase social support may improve women's experiences and lessen their grief response.

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Implications—The nature and course of grief after second-trimester termination for fetal anomaly are, as of yet, poorly understood. With improved understanding of how women grieve over time, clinicians can better recognize the significance of their patients' suffering and offer tools to direct their grief toward positive coping.

Keywords

Abortion; Second-trimester abortion; Pregnancy termination; Fetal anomaly; Perinatal grief; Pregnancy loss

1. Introduction

Approximately 150,000 women in the United States are diagnosed with a fetal anomaly each year [1,2]. Between 47% and 90% of these women choose to terminate the pregnancy [3–6]. For many, the diagnosis is devastating and unexpected [7]. One study found that 17% of women undergoing termination of pregnancy for fetal anomaly had symptoms of posttraumatic stress disorder as far out as 2 to 7 years postprocedure, indicating an extremely severe grief response [8]. Because women terminating for a fetal anomaly are often choosing to terminate highly desired pregnancies, it is possible that their grief response may be particularly difficult and thus may require more nuanced counseling [9]. Though most patients in this situation receive counseling [10], there is no evidence-based guide to direct women's expectations with this process.

Few studies have examined how women experience grief over termination for fetal anomaly and how their grief changes over time. Previous research in this population has shown that the immediate grief response is different from the grief response several months or years after the event [11]; however, narrative descriptions of how women's grief processes unfold over time have not been described. While it has been shown that shame and guilt are predictors of long-lasting grief after miscarriage [12], the roles of guilt and shame in termination for fetal anomaly have yet to be elucidated. If guilt and shame contribute to grief after termination for fetal anomaly, it will be important to understand the role of stigma in how women classify and process their grief.

We conducted a longitudinal qualitative study to assess how women define and experience grief over termination for fetal anomaly and how this grief changes over time. Improving our understanding of grief after termination for fetal anomaly will aid in the development of an evidence-based approach to counseling women who face this diagnosis, with the goal of promoting healthy coping. It will also help clinicians better address the significance of their patients' losses and provide anticipatory guidance about the course their grief may take.

2. Materials and methods

From March 2012 to October 2013, we recruited women who were undergoing second-trimester abortion for fetal anomalies or other pregnancy complications, such as preterm premature rupture of membranes (PPROM), fetal demise or maternal complications for a longitudinal qualitative study of decision satisfaction, grief and coping. Because grief associated with termination may differ according to the reason for termination, we limited

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the analysis of the grief response to women terminating for a fetal anomaly. All women were presented with the option of dilation and evacuation (D&E) or induction abortion and were allowed to choose their preferred method. We recruited and consented women at the procedure site the day of or before the procedure. Women eligible for the study were between 14 and 24 weeks of gestation, over 18 years of age and English speaking. We enrolled study participants until we reached saturation of themes. The study was approved by the University of California, San Francisco, Committee on Human Research and University of Michigan Institutional Review Board.

We recruited women from four sites (two outpatient hospital-based clinics that provide D&Es and two inpatient labor and delivery wards that offer inductions) within two academic institutions, one in Northern California and one in Michigan. Although participants' counseling regarding method options before referral was variable, the enrollment sites uniformly offered options counseling about both methods prior to the procedure.

Subjects participated in a longitudinal qualitative study, consisting of three phone interviews over 1 year. We conducted the first interview at 1 to 3 weeks after the procedure, the second at 3 months and the third at 1 year. We asked participants open-ended questions regarding their experiences with receiving the diagnosis, counseling, options discussed, decision factors, and grief and coping after the procedure. This analysis focuses on the themes related to their grief response and how their grief changed over time. We used the same semistructured interview guide for each interview but asked open-ended questions and encouraged participants to direct the interview toward what they felt were salient aspects of their experiences. We chose to conduct individual interviews instead of a focus group because of the personal and stigmatized nature of abortion. We felt that individual interviews would allow women to more fully express their emotions without feeling pressured or judged by other women's responses.

We audiorecorded, deidentified and transcribed all interviews. Two authors (M.M., J.K.) analyzed the interviews using grounded theory approach [13] in QRS NVivo 10.0 software to identify themes as they developed. As novel themes emerged in the analysis, we incorporated them into the interview questions. We compensated study participants with a $20 gift card for each of the first two interviews and a $40 gift card for the final interview.

3. Results

We enrolled 19 participants in the study. Three participants' interviews were not used in the analysis of grief because they terminated for reasons other than fetal anomaly (PPROM and fetal demise). Of the 16 eligible women (12 D&Es and 4 inductions), 3 were lost to follow-up before completing the first interview (2 D&Es and 1 induction), leaving 13 women and 35 interviews for analysis (10 D&Es and 3 inductions) (Table 1). Eleven women completed all three interviews, and 2 women (1 D&E and 1 induction) completed only the first interview.

Based on the language employed by our participants, our working definition of grief was mental suffering because of loss. Grief was universally reported at the initial interview, had

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largely subsided by 3 months and had completely subsided by 1 year. Prominent themes related to grief included self-blame, guilt, social isolation and triggers of grief.

3.1. Self-blame

Self-blame was an early manifestation of grief, with participants feeling responsible for the anomaly (Table 2). One woman worried she caused the baby's anomalies by being nonadherent to her medication (quote 2.1). Another participant recognized that she could not have prevented the outcome (quote 2.2) but continued to struggle with feeling responsible (quote 2.3). Women both understood the anomaly could not have been avoided and considered themselves at fault.

Another manifestation of self-blame was connecting one's bad decisions to the anomaly (quote 2.4). This particularly personal theme was perceived as more painful than other instances of loss in which one's behaviors were not as easily attached to the loss itself (quote 2.5). Self-blame was common and contextualized by women having had mixed feelings about the role they played in the pregnancy outcome. This point is underscored by participants' relief in being told they had no role in causing the anomaly (quotes 2.6, 2.7). Self-blame was a shared aspect of the grief experience and served as a mechanism by which women tried to explain their circumstances.

3.2. Guilt

Women experienced guilt in relation to their grief and described feeling overwhelmed by having to make the final decision to terminate a desired pregnancy (Table 3). This was most prominent in the first 3 months, with their perceived responsibility in determining the pregnancy outcome contributing to feelings of guilt and grief. A certain and lethal fetal prognosis actually eased grieving, possibly through mitigating that sense of responsibility (quote 3.1). Another woman highlighted that viewing the process as a loss due to accident or "God's will" made it easier to cope than viewing it as a termination (quote 3.2).

Women who expressed active grief at 1 year also expressed intense feelings of guilt around the decision to terminate (quotes 3.3, 3.4). Other women achieved earlier guilt resolution by changing the way they viewed their role in the termination. One example of this was women describing induction termination as something other than an abortion as a way to assuage guilt (quote 3.5).

3.3. Social isolation

Social isolation contributed to participants' experience of grief (Table 4, quote 4.1). This source of grief continued into the second interviews but had largely abated by the third interviews. At 3 months, women continued to endorse the feeling that theirs was a socially unacceptable type of loss. One woman described feeling isolated in trying to find the right space in which to grieve (quote 4.2). This woman used the term "miscarriage" rather than "termination" or "abortion" as a more socially permissible way to talk about her experience. Speaking about "abortion" would implicate the woman in choosing to end a pregnancy, whereas our participants felt they had no choice.

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One woman endorsed feeling abnormal and unable to talk about her loss (quote 4.3). Sharing one's story invited others to share their stories, thus establishing social connection and easing the burden of social isolation (quote 4.4). Although initiating that conversation was difficult, it was a crucial step for breaking through the social isolation and alleviating grief.

Women referenced support networks as a potential outlet for their social isolation and expressed frustration that they had inadequate exposure to such networks (quote 4.5). They described a need for support networks that were specific to their situation, suggesting that general support groups did not adequately address their unique grief.

3.4. Triggers

Although grief faded over time, certain experiences triggered feelings of grief even at 1 year (Table 5). Triggers included reminders of pregnancy such as baby clothes, seeing pregnant women and babies, and planning future pregnancies (quotes 5.1, 5.2), experiences that led to feeling devastated anew. Another woman described the nearly ubiquitous feeling of grief upon seeing other pregnant women or babies (quote 5.3). This quote illustrates the dissonance women felt when previously joyous experiences instead brought grief. While seeing babies unanimously was described as a trigger for grief in the first two interviews, women returned to feeling comfortable around pregnant women and babies by the third interview (quote 5.4).

Focusing on a new pregnancy was a prominent subtheme related to grief. Thinking of a future pregnancy triggered anxiety for some (quote 5.5), and in several cases, that anxiety was severe enough to change the woman's reproductive plans (quote 5.6). However, most women saw a future pregnancy in a positive light and anticipated that a healthy, normal pregnancy would bring resolution to their grief (quotes 5.7, 5.8). Three of our participants were pregnant by the end of the study and cited this as a major contributor to their grief resolution.

4. Discussion

Consistent with studies of pregnancy loss [12,14], we found guilt and self-blame to be prominent themes related to grief after termination for fetal anomaly. We also found that guilt and self-blame began to diminish between 3 months and 1 year. Initially, participants described guilt as a painful feature of their grieving process. This may be due to stigma surrounding abortion with guilt and self-blame representing internalized stigma. The social isolation experienced by our participants also appears to stem from real and perceived stigma around termination, which has been shown to compound the grieving process [15]. Women who used language distinguishing a D&E as an abortion and induction as something other than an abortion may have done so in response to stigma and as a mechanism to alleviate guilt. It is possible that classifying induction this way offers a way for women to feel as if they were not the agent who ended the pregnancy, but rather a passive participant in a predetermined process — the process of a pregnancy that was fated to not survive. It has previously been shown that some women feel more comfortable using passive language

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such as “loss” or “miscarriage” when disclosing the circumstances around their termination [16].

The use of language around abortion was the only theme that emerged as different between women who chose D&E and those who chose induction. It is possible that we could have seen themes related to grief expressed differently between these women had we enrolled more women who chose induction. Consistent with our findings, a quantitative study of grief resolution after D&E or induction for fetal anomalies reported no difference in grief resolution between those who choose D&E versus induction [17]. One interpretation is that women assist their own grief resolution by choosing a method that is most congruent with their emotional coping style [18]. Previous studies have also shown that talking about pregnancy loss with loved ones can move the grieving process along and that lack of social support can prolong and complicate the grief response [15]. In our study, women described social support as a key element to recovery; however, they simultaneously said that discussing the termination was extremely difficult. This social isolation likely reflects abortion stigma, as previous studies have found that talking about the miscarriage can ease the grieving process but that discussing abortion is seen as too personal and too taboo [19].

We found that emotionally stressful grief triggers were quite common among our participants, even after 1 year, a finding that is supported by studies of women who have experienced pregnancy loss [20]. These experiences likely are upsetting because they represent tangible evidence that these women will not experience the anticipated role change from that of a pregnant woman to that of a mother. The diagnosis and termination force them to change the projection of their future role to one of a bereaved woman rather than a mother [21]. In the literature surrounding other types of grief, there is a well-documented phenomenon known as the anniversary reaction [22,23] in which grief that had been subsiding reintensifies on the date of the person’s death. Women in our study described a similar experience in which their grief would reintensify on the date of the termination or the due date. Awareness of this phenomenon may lead to improved counseling through providing women with anticipatory guidance regarding the course of grief.

The grief-related themes that emerged in these longitudinal interviews are specific to our studied population, and while they may provide insight to other women terminating for fetal anomalies, our data may not be generalizable to other populations. It is notable that 3 of the 16 women who initially enrolled in the study could not be contacted before the first interview. It is difficult to know if these women’s grief responses were different from those who we were able to contact. Regardless, it is likely that these women chose to not process their grief through participating in these interviews. While preliminary and qualitative in nature, our results provide the beginning of a roadmap for understanding women’s grief trajectories when terminating for fetal anomalies and may have implications for improving pre- and postprocedure counseling.

Our results emphasize the need for counseling interventions that include anticipatory guidance about grief; the manner in which to best counsel patients about self-blame, guilt and social isolation that will likely punctuate the grief experience has yet to be elucidated. At a minimum, counseling should include information about the nature and duration of the

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grief they should expect, as women have reported desiring this type of information [24]. Normalizing the decision to terminate may help women navigate their subsequent grief related to feeling isolated and abnormal. Additionally, women may benefit from support groups or online forums, as many women described a desire to be connected with others who had undergone this specific experience. Our results are consistent with other findings that 72% of couples choosing termination for fetal anomaly would have appreciated the opportunity to speak with other couples in their same situation [25]. To combat social isolation, counseling may be needed to help patients preemptively identify sources of social support.

Grief after termination for fetal anomaly is common and may be complicated by self-blame, guilt and social isolation. Efforts to decrease abortion stigma, connect women to appropriate support networks and develop pre- and postprocedure tools may improve women's grief experiences and ultimately improve their emotional recovery.

Acknowledgments

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Table 1

Characteristics of participants

Characteristics	N (%)
Total	13
Age (median)*	31 (1.5)
Gestational age weeks (mean)*	20.3 (3.1)
Primigravid	6 (46)
Nulliparous	8 (62)
Ethnicity	
White, non-Hispanic	7 (54)
Hispanic	4 (31)
Black	1 (8)
Asian	1 (8)
Reason for termination	
Genetic anomaly	5 (38)
Structural anomaly	8 (62)
Method chosen	
D&E	10 (77)
Induction	3 (23)

*Mean (SD) or median (SE) reported.

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Table 2

Quotes related to the theme self-blame

Self-blame		
Quote #	**Quote**	**Source**
2.1	Maybe it was because… I was really bad, I wasn't really settled with my epilepsy. I was always in the emergency room.	Participant 7, interview 3
2.2	So it's nothing I could've [done to] rewind time, the doctor said there's nothing I could've did so there's no point of me feeling bad, even though it's hard for me not to because it's my child.	Participant 13, interview 1
2.3	I found out folic acid is another reason why a baby can have acrania… So I was thinking maybe it was that with me because I am a picky eater.	Participant 13, interview 2
2.4	I feel like maybe God's punishing me because I chose to do that [an elective abortion in the past].	Participant 18, interview 1
2.5	My dad passed away and it was a major loss and I never feel like… I caused that… This time I feel like I… caused it or if I would've not [been] this overweight or if I would've taken the folic acid.	Participant 1, interview 1
2.6	It was reassuring, just the information that they had given me that it's something that couldn't have been predicted. It's just something that happens and that was a lot easier to cope with than thinking it was something I had done wrong.	Participant 17, interview 2
2.7	Just to know that… it's not something that they're doing just because. It's not that they want it… they're terminating because of a reason. And like they told me, it's not my fault. It's not something that I did wrong, it just happened.	Participant 9, interview 1

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Table 3

Quotes related to guilt

Guilt		
Quote #	**Quote**	**Source**
3.1	[The doctor] told me afterwards that the baby's heart was hardly beating… once he said that to me, it looked like a huge weight was lifted off me… I felt validation that this was what I had to do. This was [the] inevitable way that this was going to play out… that was my biggest fear. I'm like oh God, if they happen to find it was normal I'll never be able to live with myself.	Participant 18, interview 2
3.2	After the surgery they told me that the baby had passed away before the surgery. So, that kind of helped because I didn't feel like we did it or the doctor did it… I felt, like, God did it and that was what He wanted.	Participant 14, interview 2
3.3	I'm still not sure that it's the correct decision, that's the worst part.	Participant 5, interview 1
3.4	We'll always have the question, you know, whether we made the right decision or not.	Participant 5, interview 2
3.5	When I was first told that [with] the D&E the baby wouldn't completely come out whole, I just viewed that more like an unwanted pregnancy, like an abortion, and the labor procedure was more like, you know a pregnancy. I wanted it, I wanted to keep my pregnancy and make it as much as I could, as a real pregnancy, versus an abortion. I think it [the induction] eases it [the grief] a little bit because in my mind it feels like I delivered the baby, but for some reason or another, you know, it didn't survive.	Participant 10, interview 1

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Table 4

Quotes related to social isolation

Social isolation		
Quote #	**Quote**	**Source**
4.1	I feel very alone. I mean, I have my husband which is wonderful. But … I'm sure he gets exhausted from hearing about it.	Participant 18, interview 2
4.2	[It is an] interesting realization that some grief is really public … If I'm crying over my grandfather, people will be like, "Oh, I'm so sorry." I can't imagine even responding by saying, "Oh, I'm crying because I had a miscarriage." Like you just wouldn't be public in that way about that kind of grief… it just kind of highlighted what is acceptable to be public about and what's not.	Participant 8, interview 2
4.3	When I talked to one of our friends, I found out… actually there are a lot of people who experience that, and they just don't tell because it's not something you talk about… [If you] start to tell people about what you experience [then] they would say, "Oh, yeah. I know. We had one baby before and we lost [it too.]"	Participant 14, interview 2
4.4	Having to initially tell somebody was kind of hard, but if they already knew, then it was kind of like the icebreaker… having to actually say those words I guess was the hardest part.	Participant 15, interview 3
4.5	I wish I could get into a [support] group where it's more related to that specific situation… if I was in a group with a lot of women… [who had] lost their babies to the same thing, like, genetic diseases or acrania… That would be more coping for me than… a group that they just lost their children.	Participant 13, interview 2

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Table 5

Quotes related to triggers of grief

Triggers		
Quote #	**Quote**	**Source**
5.1	I'm still a little sad about it because… I have this app that was for… tracking the pregnancy, and then when I got pregnant again, I logged back onto that baby center… and then it was like, oh, you're baby is six months old… and I was kind of like oh… I would have had that baby right now. That kind of was… hard to do and see.	Participant 17, interview 2
5.2	Sometimes I do remember because I see baby clothes. My mom gave me some baby outfits and I when I see it … I get sad.	Participant 1, interview 3
5.3	I just try to keep away. I feel like that's a little bit easier for me, not looking at the babies, not holding them… Not that I want to be like that, because I love babies. But I can't right now.	Participant 18, interview 2
5.4	Right now one of my friends is pregnant, and I'm helping her. I'm telling her to drink a lot of water, to not be in the sun too much because that's bad for her. So, I'm really doing well with that. But, like, when it barely happened last year… I couldn't see pregnant women, kids running around. So, it was really bad for me the few months after it happened.	Participant 7, interview 3
5.5	I'm thinking about getting pregnant again, though that does kind of scare me a little bit. We worry that it'll be the same problem again.	Participant 1, interview 2
5.6	[To] have another pregnancy would make me real conscious on everything. And I probably would think twice now about even becoming pregnant because I would be scared.	Participant 13, interview 2
5.7	Even though there were times when I was very anxious about being pregnant [again] and about having children, I think that [a future pregnancy] is a big part of the closure for me.	Participant 11, interview 3
5.8	I am moving forward with all the reproductive stuff with my doctor… I was like, 'Tell me as soon as my body is ready; I'm ready to go.' It definitely felt like coping.	Participant 8, interview 2